



The UK Network  
of Dementia Voices



Innovations  
in Dementia

## **Dementia and Disability - APPG 2018 call for evidence**

### **Response from and on behalf of Innovations in Dementia and DEEP (The UK Network of Dementia Voices)**

#### **1. Our views on dementia being identified as a disability**

Many people struggle to think of their dementia as a disability, and are understandably reluctant to accept another 'label' on top of 'dementia' - itself not much-loved! But dementia *is* a disability under the Equality Act, DDA and UNCRPD definitions. Other groups e.g. people with mental health difficulties, who don't consider themselves as disabled either, have used the legal definition effectively to claim their rights.

The word 'disability' is therefore not a stigmatising label imposed upon individuals, but simply a means to an end, a tool.

#### **2. Are people with dementia treated differently to people with other health conditions or disabilities?**

Very much so. They tell us that they have:

- not been given a diagnosis, because the clinician doesn't think there is any help s/he can give

- (or) been given their diagnosis in a very negative way, made to feel they should simply prepare to die
- not been given any post-diagnostic support or told about entitlements, peer support, other services
- found much information inaccessible e.g. too complex or only online
- not been offered rehabilitation or counselling to adapt to their condition
- been pressured into leaving work, without an assessment - yet denied exemption from the 'Work Capability Assessment' process
- (if they do get services), been means-tested because these are defined as social not health care - even though they have a physical brain disease
- been expected to put up with unskilled, non-specialist and discontinuous care
- been rushed through toileting/eating because they only have a 15 minute care slot
- been put at risk of loss of function, depression, loneliness, lack of vitamin D etc because they haven't been supported to go outside
- been assumed to lack capacity to make small or big decisions, without the necessary assessment
- been denied recognition of their mobility/sensory issues, and other co-morbidities
- been expected to function in environments which are overwhelming and oppressive for them because of their dementia
- been treated with impatience, insensitivity and ignorance – even by 'professionals'
- been denied benefits because their cognitive issues are ignored
- been refused mortgages or insurances
- been medicated or restrained, rather than given skilled support for their distress responses
- had nutritional, hydrational, health, pain needs ignored because they cannot communicate them easily
- been denied a Blue Badge, because dementia alone is not seen as a disability
- been routinely described as burdens, victims, sufferers, 'bed-blockers'

- been denied a stair lift or personal assistant, because of their dementia (blanket policies)
- been forced to move into a care home against their wishes and though lack of any other option
- ... and possibly split up from their partner for the first time ever
- been labelled as 'Do Not Resuscitate' while in hospital, without their knowledge
- been denied opportunities to share their expertise in service planning/ design
- (or) been involved 'tokenistically', or left out-of-pocket
- been denied access to end-of-life hospice services.

Finally, people affected by dementia may also face intersectional discrimination e.g.

- Ageism (different treatment for different ages)
- Sexism (careless assumptions about either men or women)
- Discrimination on sexual orientation (e.g. no hospital visiting rights for same sex couples, or involvement in decisions for partners).

These clear examples of direct and indirect discrimination contravene their human rights. Yet they often feel powerless against such discrimination and unable to insist on their legal entitlements. And they may be reluctant to frame their issues in terms of rights, even if they know them.

### **3. ... what else do people need in order to continue to live well?**

They need an approach based on:

Recognition of their human rights (not defined by funding constraints)

Positive risk-taking

'Social' not 'medical' model

Listening – recognition of their expertise

Being enabled to contribute

Inclusion

#### **4. What are the main challenges that people affected by dementia face in day-to-day life?**

Prejudices - negative attitudes - being disbelieved (especially if younger)  
- lack of training of professional staff - discriminatory attitudes by public sector staff - lack of awareness in general public – mockery/bullying

Inaccessible public transport - driving – parking (Blue Badges) – airports  
– poor signage – complex information

Exclusion from independent living/community- benefits and other entitlements (especially PIP) – lack of access to community services

Inaccessible care – inept diagnosis – lack of continuity of healthcare – poor or no post-diagnostic support - inaccessible healthcare – poor quality of care in hospitals and care homes – lack of access to rehab

Work and employment – ignorance of reasonable adjustments

#### **5. ... what future action do you think needs to be taken to address these challenges?**

There are pockets of good and even exceptional practice.

But current support is often: non-existent, inconsistent, unintegrated, overly-traditional, rigid not flexible, task-based not person-centred, unimaginative, inappropriate for age, 'post-code lottery', unaffordable, gate-keepered, stigmatising, medical not social model, poorly publicised, hard to get to, anti-couple, deficit rather than asset-focused.

In short, not what most people want...and more trouble than it's worth.

Priorities should be:

Leadership from Government and at all levels in acknowledging the rights of people with dementia as disabled people.

Investment in greater public and professional understanding of dementia, including young onset, based on the social not medical model of disability. Including attention to imagery and language.

Radical review of how diagnosis is delivered.

Review of the provision of follow-up healthcare and post-diagnostic support/information so that it is fully tailored, and available everywhere.

Consistent signposting to peer support and other community resources.

Education of employers that people with dementia have the right to continue to work for as long as possible.

Requirement on transport providers, Blue Badge assessors, local authorities to review staff attitudes and arrangements (regarding travelling, parking and driving), so that all people with dementia can exercise their right to get out and about.

Review of the impact of benefits reassessments and cuts on the ability of people with dementia to live independently, and, in the words of the Dementia Strategy, to 'live well with dementia'.